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ABSTRACT

This study compiled descriptive information about what states are doing or planning to do with early intervention data systems, a component of early intervention systems as specified in Part H of the Individuals with Disabilities Education Act. The study examined the uses of data systems in eight states: Colorado, Maine, Maryland, Massachusetts, Missouri, North Carolina, Ohio, and Texas. The study found that the state response to the requirement to establish a data system has taken many forms. Among the dimensons on which state data systems differ are: the level of governance (local, state, federal) for which the system was designed to provide information, the kinds of data being collected, the point in the information flow at which data are computerized, how data are transferred from the local level to the state, the type of reports generated from the data, and the capability of the system to address federal reporting requirements. State agencies are using their data systems to oversee service delivery by local programs, to bill for services, and to respond to federal reporting requirements. Local programs are using management information systems to improve the delivery of early intervention services. The report closes with a summary, a set of recommendations; and synopses of information about each state's early intervention system and data system. (JDD)

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Carolina Institute for Child and Family Policy

# DATA SYSTEMS IN EARLY INTERVENTION

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Ec 301 872

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# DATA SYSTEMS IN EARLY INTERVENTION

Kathleen Hebbeler

February, 1993

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## EXECUTIVE SUMMARY

Congress established the Program for Infants and Toddlers with Disabilities, Part H of the Individuals with Disabilities Education Act (IDEA), to expand the availability of early intervention services. The law prescribes 14 components of an early intervention system that are to be implemented in each state. The last of these components is a data system. This study compiled descriptive information about what states are doing or planning to do with their early intervention data systems. The study looked at how early intervention data are being used at both the state and local level.

As author, I examined in depth data systems in eight states (Colorado, Maine, Maryland, Massachusetts, Missouri, North Carolina, Ohio, and Texas). I collected written and verbal information from these states, supplementing it with information about other states that I had obtained while employed by the Office of Special Education Programs in the U.S. Department of Education. My responsibilities in that office included managing the collection of the federally required data on early intervention, which involved substantial communication with the state staff who oversaw data collection in their respective states.

The state response to the requirement to establish a data system, like the state response to the other required components of an early intervention system, has taken many forms. States have elected to use contrasting approaches to collect different kinds of data on early intervention and to organize it in different ways to accomplish different objectives. Dimensions on which state data systems differ include: the level of governance (local, state, federal) for which the system was designed to provide information, the kinds of data being collected, the point in the information flow at which data are computerized, how data are transferred from the local level to the state, the level of data available at the state, the type of reports generated from the data, the nature of the relationship between state agencies and local programs, the capability of the system to address the federal reporting requirements, and the number of data systems operating in the state.

States agencies are using information from their data systems to oversee service delivery by local programs, to bill for services, and to respond to the federal reporting requirements. In carrying our their oversight responsibilities, state agencies use early intervention data to describe whom they are servicing and the services being provided, to identify weaknesses in the service delivery system, to plan for the future, to build linkages across jurisdictions, and to answer a variety of questions about early intervention in the state. Lead agencies are also sharing data with state legislatures to help them understand the need for early intervention.

Local programs are using management information systems to improve the delivery of early intervention services. These systems generate statistical reports on their clients; produce lists of children or sub-sets of children organized in a variety of ways; monitor the status of services to individual children and families by, for example, providing a reminder about a required upcoming event on the Part H timeline; produce copies of a child's record including the IFSP; provide links to information about other resources in the community; generate transition-related information for school districts that will be receiving the program's 3 year olds;

transmit data to the state; and perform routine clerical functions such as generation of letters or labels.

The following recommendations were made to assist states in developing a data system that will be a useful tool in building and improving a state-wide early intervention system:

**1. An early intervention data system should be driven by information needs of state and/or local staff.**

This rather obvious recommendation served as the basis for this report. As obvious as the recommendation may appear, it has its origins in conversations I have had with state staff whose data systems appeared to be driven solely by the federal reporting requirements or by a data system developer who was unfamiliar with early intervention. Furthermore, some states seemed to start with the data elements themselves rather than with the purposes they wanted the data system to achieve or the questions they wanted it to answer. Identifying up front all the possible ways in which information could improve the provision of early intervention is not an easy task but it is a lot easier and far more cost effective than revamping a data system that isn't meeting important state or local needs for information. Collectively across the nation much good thinking has already been done, as exemplified by the eight states highlighted in this study.

**2. States need to create an "information culture" to enable data systems to benefit service provision.**

Data systems don't convert data to information; people do. The people who interact with the data system by providing, receiving, analyzing, or interpreting the data have the capability to either increase or decrease its value. State agencies communicate the value of data in many ways, including providing sufficient resources to support the implementation of the data system, disseminating data to local programs and the public, and using its information for decision-making. State agencies can also devalue data by not feeding it back to local programs, by not letting local programs know the purpose of data collections, and by not using information in the management of state programs. Any state that is interested in using information to improve early intervention services must concern itself with more than hardware and software issues. The extent to which a culture has been created that supports the production and utilization of data will ultimately determine the worth of the data system.

**3. States need to utilize a variety of approaches to obtain the information they need.**

Most of the states examined as part of this study were using more than one way to collect the information they needed. Many had a client-level data base that provided much crucial information on early intervention, but this data base was supplemented by other data collections as well. Not all information, such as personnel information, is tied to individual children, so alternative approaches may be more appropriate. States may be able to realize substantial efficiencies in their data collections if they don't try to answer all questions through a single data

system but rather develop a variety of approaches tailored uniquely to the information needed.

**4. States need to maintain a balanced perspective about the amount of error in the data they collect.**

Too often data are totally disregarded because they contain some degree of error. Perfection is a noble goal, but in the real world it is not always possible. It may not even be desirable if substantial human or resource costs are encountered merely to achieve added precision that is of no consequence for making decisions. While data that are 100% accurate are obviously the ideal, approximations may be better than no data at all. It is necessary to start somewhere to build an information culture; belittling whatever data are available ultimately may be counterproductive.

The varied and innovative uses of data systems documented in this report constitute a body of evidence that the investment in a data systems has the potential to ultimately add to, rather than subtract from, the limited pool of resources available for early intervention. By exploiting the power of information and the computer's power to manipulate it, some states have found ways to increase the efficiency and effectiveness of their early intervention system. In these times of tight budgets, many states are being asked to serve more families without substantially more money. A well-conceptualized and implemented data system can free staff from tasks the computer can do and allow the staff to spend more of their work hours doing things that only people can do.

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Thinking about early intervention services for infants and toddlers with disabilities and for their families brings many images and related phrases to mind: service coordination, therapies, Individualized Family Services Plans (IFSPs), home visits. Missing from most people's list of humane associations are such cold items as data forms, computers, printouts, and floppy disks. Numbers and babies may seem far apart but, as many states have already learned, the effective production and utilization of information can play a pivotal role in the provision of early intervention services.

## Part H and Data Systems

Congress established the Program for Infants and Toddlers with Disabilities, Part H of the Individuals with Disabilities Education Act (IDEA), to expand the availability of early intervention services. The law requires that each state develop a statewide comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities and for their families. Fourteen components of an early intervention system are prescribed in the law. The last of these components requires states to develop a data system:

> a system for compiling data on the numbers of infants and toddlers with disabilities and their families in the State in need of appropriate early intervention services (which may be based on a sampling of data), the numbers of such infants and toddlers and their families served, the types of services provided (which may be based on a sampling of data, and other information required by the Secretary (Sec. 1476 [b][14]).

The data system component of Part H stipulates that the state's data system must be able to report several kinds of information about infants and toddlers in early intervention: the number in need of service, the number receiving service, and the type of service provided. Additional data requirements (e.g., personnel data) are contained in section 1418 of IDEA[1]. Except for being able to supply these required data, the parameters of the data system are left entirely up to the state. The particular wording of the data component suggests that Congress was interested in having information from states for program accountability purposes. There may also have been a presumption that data systems would improve the operation of the state early intervention system. The open-ended nature of the data system requirement suggested that state data systems would take many different forms as states set about planning for the implementation of Part H.

## Studying State Data Systems

This reports contains descriptive information about the kind of early intervention data being collecting by states and the multiple and varied ways in

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1 Under section 1418, states have been required to submit data on special education students ages 3 through 21 for over fifteen years. When P.L. 99-457 was passed in 1986, it amended Section 1418 to include data on early intervention, as well.

which they are using these data to improve service delivery. The study looked at how early intervention data is being used at both the state and local level.

Purpose of the study. A key hurdle to using data systems with maximum efficiency was the lack of a crystal clear sense of the needs of, and expectations from, the data system. Our hope was that by assembling examples of what some states are doing with their early intervention data, other states could be in a better position to clarify or elaborate their vision for a data system.

This report presents numerous examples of what states are doing or planning to do with early intervention data. The study made no judgments about the appropriateness or usefulness of the various approaches. I have also included information on functions that are not yet operational because the intent was to show the potential of data systems. Documentation of some of the varied state applications of data systems may prove itself helpful to others interested in data issues to build -- either conceptually or through a computer application -- on the current knowledge base.

States studied. I examined in depth the uses of data systems in eight states (Colorado, Maine, Maryland, Massachusetts, Missouri, North Carolina, Ohio, Texas) as part of the study. I selected these states because collectively they represent a variety of approaches to data systems. Appendix A contains "State Capsules," which synopsize general information about the state, a brief description the early intervention system, and a description of the data system. Elements of the eight data systems are also presented throughout the report. Although the study is focused on states' use of data, the reader may have difficulty understanding the use a state is making of its data without some information about the data system itself and the context in which it is operating. The capsules present this additional information. In addition to the eight states that were examined in depth, I have included issues related to data systems from other states where appropriate, although no other states are mentioned by name.

Sources of information. I derived the information contained in this report from two sources. The primary source was state material, either documents or conversations, from the eight states that were studied. Written materials reviewed included the state application to the U.S. Department of Education for Part H funding, and written materials related to the data system (e.g., manuals, memos). I based subsequent discussions with state staff on issues that were not addressed in the written materials. Because the content of the written materials describing the data system varied as much as the data systems, each of these discussions was unique to the state.

My general knowledge of state data systems, acquired during my four years of working with state personnel on data issues, provided a second source of information. There is no way to verify the validity of this information, because it reflects entirely my own particular perspective on data issues.

Organization of the report. The report consists of three main sections followed by a summary and recommendations. The first section presents an overview of data systems and data issues across the states. The second section

describes some of the ways in which early intervention data are being used at the state level. Examples of state-level uses of data include describing the population of children being served statewide or tracking service trends to make projections for the future. The third section of the report focuses on the use of data at the local program level. In this section, I describe how three states are using data to enhance service coordination. The report closes with a synthesis and set of recommendations.

Although state and local level uses of data have been separated for the discussion, some of the uses of data can be very similar. For instance, statistical data about the characteristics of the children served are produced at both the state and local levels. At the state level, the information may describe children across 25 counties, whereas at the local level, the information may describe children across six program sites. The exact same piece of information can be put to many different uses, depending on how it is presented and who is using it. Furthermore, the usefulness of data on early intervention services is direct and obvious for some kinds of information -- for example, data from information management systems that remind service coordinators to begin transition planning because a child will turn three in the coming months. The benefit of other kinds of information may be less direct (especially for those submitting the data) but no less consequential -- for example, the data used to prepare reports for the state legislature to justify program funding. Submitting these data to the state is ultimately of great value to local programs even though local staff may not be aware of its use.

Information on early intervention has several overlapping uses at both the state and local level. Many of the state uses of early intervention data related to program administration have a corresponding use at the local level (e.g., both levels need data for planning). I have structured the discussion of local uses of a data system primarily around the uses that relate to the provision of services, a uniquely local function. Many of the data uses discussed in the state sections are common to both the state and local levels.

## Overview of State Data Systems

A data system is a way to produce information. According to Stephenson (1985), *data* are raw, unorganized facts, figures and observations that are meaningless individually; *Information* is data that have been organized into meaningful form. A *system* is a set of elements that operate together to accomplish organizational or personal objectives.

### Differing Dimensions of State Data Systems

States have found a variety of ways to turn data into information. States have elected to use contrasting approaches to collect different kinds of data on early intervention and to organize data in different ways to accomplish different objectives. State data systems differ in ways such as:

- the level of administration the data system was designed to serve. Some data systems were developed to meet the needs of the local programs, some to meet state needs for information about local programs. Still others

were designed primarily to allow the state to provide data for the federal reporting requirements. Many data systems are hybrids trying to meet needs for information at a variety of governmental levels although there may be a primary emphasis on local, state, or federal needs.

- the kinds of data states collect on infants and toddlers with disabilities and on their families. Some states such as Massachusetts keep extensive data on the characteristics of infants, toddlers and families in the system. Others states such as Missouri know less about the child or family but have a great deal of information about the services, the service providers, dates, insurance, and costs.

- the point in the information flow at which the data are computerized. In some places, including the three states described in the section of the report on local uses, data are computerized at the local program level. In other states, such as Texas and Massachusetts, data are entered into a computer and analyzed at the state level. Local programs, of course, may opt to set up their own automated data system for program management regardless of how the state collects data.

- how data are transferred from the local level to the state. Early intervention data go from local program to the state via paper, floppy disks, modems, or a direct connection to the state's mainframe. Each method was represented among the eight states studied.

- the level of data available at the state level. Some states collect only aggregated data from local programs, whereas others have non-identifiable individual child and family data. Still others have personally identifiable data on the child and family. "Aggregated data" means the data have already been summarized to a program or county level before being sent to the state. For instance, County A reports that 56 children received early intervention services. "Non-identifiable individual data" means the state has a set of information on each child and family, for example, date of birth, gender, diagnosis, etc., but not the child's name. Instead of one record for County A containing the total count, the state would have 56 records with information about each of the children. "Personally identifiable information" would contain the same 56 records plus some way of identifying the child, such as a name or identification number.

- the type of reports generated from the data. Some states produce printouts for the state administrators and the local programs. Some data systems provide local programs the capacity to produce a variety of reports on their own. Some states incorporate their data into polished performance reports that are distributed to others in state government and to the public. I have included some sample tables and figures from these state publications in this report.

- the nature of the relationship between state agencies and local programs. The development of data systems is one of the many areas of Part H

implementation impacted by the nature and extent of authority that rests within a given state government. Some state agencies have the capability to require the data they want when they want them from local programs. In other states, the state's ability to collect data seems to derive primarily from the good will of the local programs, which may or may not be willing to be a part of the data system. State agencies that give funds directly to local programs or pay the bills for services seem to be in a much stronger position to acquire data from local programs than are non-funding agencies. Most of the eight states featured in this report already had laid the necessary groundwork to insure the smooth and regular submission of data from the local level to the state. Other states, including a number of those not included in the study, are still developing this groundwork.

- when state data systems were developed. Some states' data systems, such as the system in Massachusetts, existed before Part H was passed; others such as Ohio's and Maryland's have been developed to incorporate requirements unique to Part H. Not surprisingly, the pre-existing systems vary in their ability to provide Part H relevant information, especially the federal reporting requirements.

- how many data systems a state has. A number of states such as North Carolina and Colorado have several data systems containing information on families receiving early intervention. Some states have a rather comprehensive primary system that still needs to be supplemented with additional data collection methodologies for certain kinds of information. Other states have several comprehensive systems that may or may not be able to communicate with one another. Many of these state-level data systems are not accurately described as data systems on early intervention. They are data systems that include information on many clients, some of whom happen to be infants and toddlers with disabilities. Some states have found themselves in the unfortunate position of having a great deal of data but very little integrated information about early intervention because of pre-existing, multiple data systems.

The next two sections of the report highlight some of the specific state and local needs for information that are being met through early intervention data systems.

### Use of a Data System by State Agencies

Even in the smallest states, Part H lead agencies are removed from the day-to-day activities that make up the provision of early intervention services. Data systems are one means of bridging the gap between the state and local level. Collecting information via a data system allows state staff to describe and track various parameters of program delivery at the local level. In addition to providing information about early intervention, data systems are being used to either perform or streamline the performance of routine state-level functions associated with the operation of early intervention programs. Examples of two such functions include billing vendors for early intervention services and submitting data to the federal government.

This discussion of state-level uses of data systems focuses on three ways in which state level administrators are using their early intervention data systems: (a) overseeing local programs (this encompasses a variety of questions states ask about the provision of early intervention services at the local level); (b) automation of the process of billing for services, as described in one state's plan to bill by linking data sets; and (c) three contrasting approaches to meeting the federal reporting requirements under Part H.

Overseeing Local Programs

State-level administrators have found a variety of ways to use information about early intervention to oversee service delivery. Data from local programs can be used to insure that Part H is being implemented as required by federal and state law and to identify areas where local programs need additional assistance. For states that are large either in population or square miles, data systems can be especially valuable tools for keeping in touch with local developments. Data systems can provide state agencies with the information to identify trends in service delivery and to forecast future resource needs. These kinds of state activities go by a variety of names: monitoring, planning, evaluation. Whatever the activity is called, the intent is to use information to make improvements in the service delivery system.

Describing clients and services. One common use of a data system in early intervention is to describe the population being served in the state and the kind of services they are receiving. There appears to be almost universal interest in knowing how many infants and toddlers are being served. After "how many," states are asking and answering a variety of other questions about their early intervention systems.

Texas and Massachusetts have very different data systems but use their data for many of the same purposes including the preparation of a report providing descriptive, quantitative information about early intervention. The Texas Early Childhood Intervention Program collects data regularly from its 77 local programs through a variety of paper and pencil surveys. These surveys generate program-level data that are compiled by the lead agency. From these data, the state prepares a periodic report containing a wealth of information about early intervention in Texas such as the ages of the infants and toddlers at referral, the referral source, their medical conditions, and the services received. The report uses figures and graphs to convey the information in an easily understandable format. Figure 1 shows a sample page from the Texas report.

The early intervention data system in Massachusetts is based on individual child registration forms, which are sent to the state and entered into the state-level data base. The annual report prepared from these data reflects the extensive demographic data on recipients' early intervention services collected by the state. Information on race/ethnicity, gender, maternal and paternal education, percentage of families in poverty, employment status, and insurance carriers of families in early intervention is presented in the report. Many of these indicators are compared to the comparable percentage for the state as a whole. The report also presents

# Figure 1

## Descriptive Data on Infants and Toddlers in Early Intervention (TEXAS)

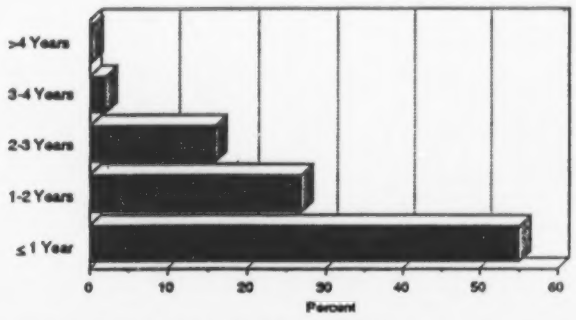
### *SERVICES FOR CHILDREN & THEIR FAMILIES*

### High Priority Infant Transitional Service Projects

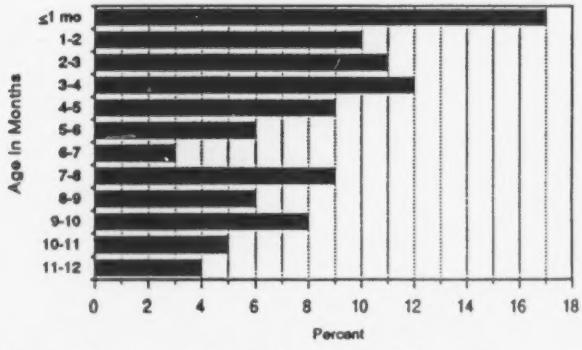
**In FY'89, 55% of referrals to ECI programs were made at or before children were one year of age, and 25% of the referrals were made before children were four months old.**

**Prolonged hospital stays or very low birth weight are indicators of potential developmental delay. Many children in local ECI programs had previous long-term hospitalizations either in neonatal intensive care units or in special care nurseries as shown in the chart below.**

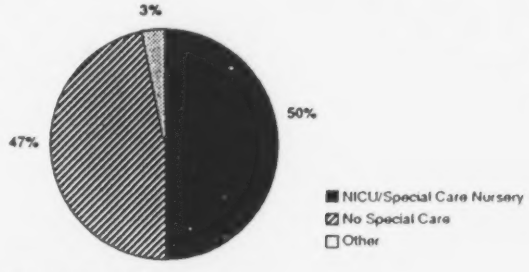
In an effort to reach more at-risk infants, the Texas ECI program is funding projects in major birth centers in Texas. These high priority infant transitional services (HPITS) projects follow infants after hospital discharge to ensure that they are screened for possible delays in development when they visit their doctors for well-baby checks or immunizations. The projects also ensure that if babies have developmental problems they are referred to ECI programs or other services as needed. Projects are planned for 20 major birth centers by FY'93.




*Age of Infants and Toddlers (in Years) at Referral, FY'90*




*Age (in Months) of Infants Under One Year at Referral, FY'90*




*Level of Care After Birth, FY'90*

Source: The Texas Early Childhood Intervention Program (1990). Helping Families from the Beginning. Austin, TX: Texas Education Agency.

information on the type of risk among children in early intervention (e.g., environmental, biological), the nature, severity, and number of the child's functional problems, age at referral, and referral source. Figure 2 shows a sample page from the Massachusetts annual report.

Data on the number of children served in each local program can be useful for state-level decisions. Ohio notes that data on the number of children served can be compared to the number of staff being requested in the local program's grant application to the state for early intervention funds. This comparison helps the state determine the appropriateness of the local program's request. As part of the review of the program's request for funding, in Texas data on children served in a local program are compared to the number of children the program intended to serve.

Costs of early intervention services is a data item of high interest to many states. In Maine, data on individual clients are entered at each local program site. Information maintained on clients includes the cost of each service and who is paying for it (e.g., the program, Medicaid, private insurance). Previously, local programs sent data to the state through hard copies of data forms and through floppy disks, but local sites can now be linked to the state office by modem. Maine can calculate costs because the data system contains information on provider costs, as well as the intensity and duration of service provided.

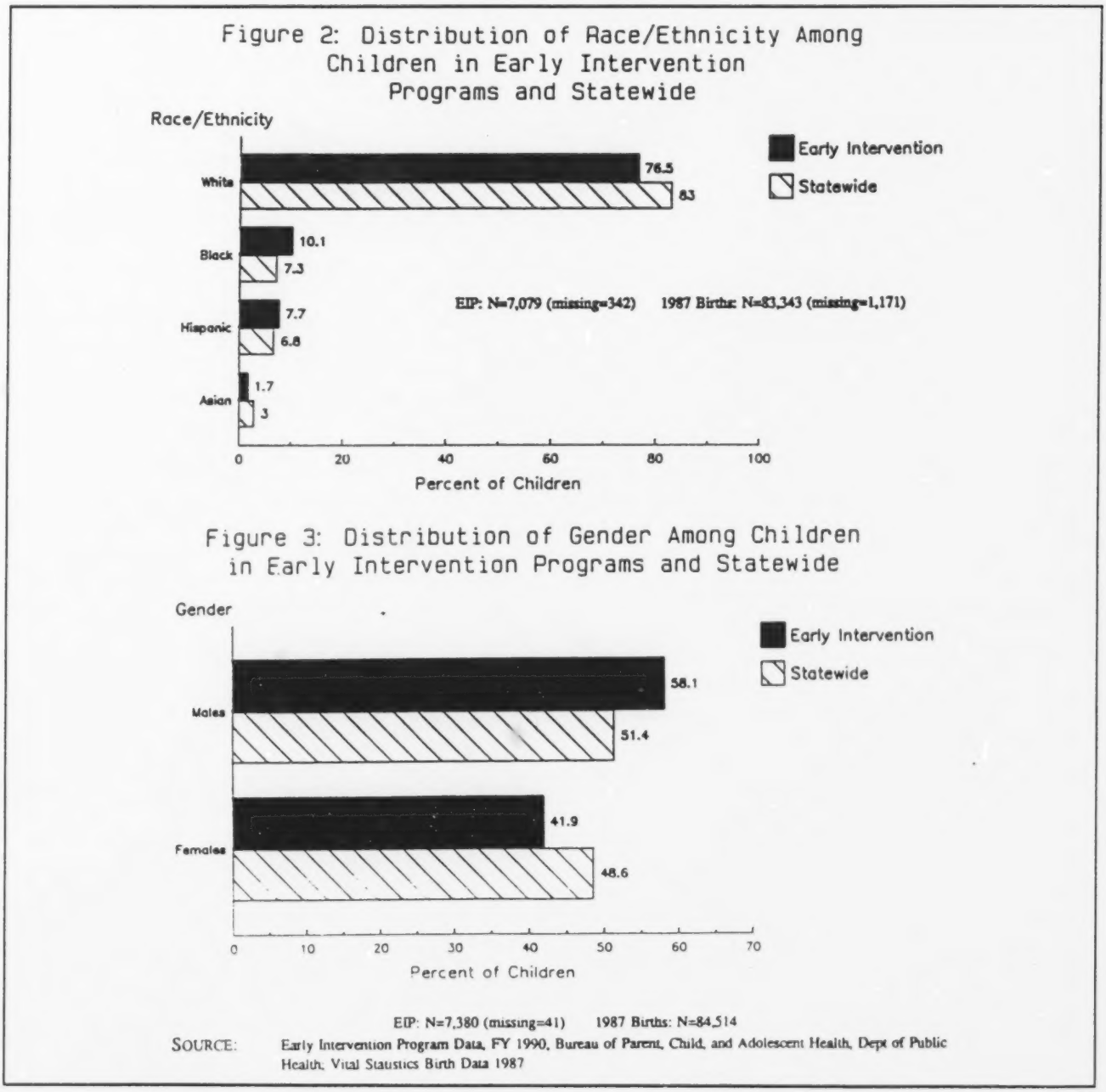
The Texas data system has and the Missouri data system will have the capability to examine costs. Texas collects monthly data from each local program on service hours by type of professional (e.g., social worker, speech therapist). Texas is currently examining its cost data to promote a more equitable distribution of resources. The most recent data showed substantial variation in per child expenditures by local programs. The Missouri data base will contain cost information because the data system has been designed to be used to bill for services (described later in this report).

Identifying holes in service delivery. Weaknesses in a service delivery system can take many forms: not enough or too many children being identified as needing services, services not provided quickly enough, or not enough services or service options available. Early intervention data systems have been designed to provide the state with the information critical to identifying weak points in its system so that targeted assistance can be provided to local programs.

A frequent concern of states is whether or not local programs have identified and are serving all the children in need of service. One approach to answering this question is to compare the percentage of children identified to a percentage of some absolute standard in order to arrive at a percentage of the population that should be receiving services. Another approach is to compare the percentage identified and the percentage being served by other local programs in the state. The question of what percentage of infants and toddlers should be receiving services has no easy answer, but a reasonable approximation can be obtained by looking at the percentages served by other jurisdictions -- if possible, other similar jurisdictions. Texas, for instance, calculates the percentage of the population

# Figure 2

## Descriptive Data on Infants and Toddlers in Early Intervention (MASSACHUSSETTS)




Source: Massachusetts Department of Public Health (1991). Early Intervention Programs: Annual Report, Fiscal Year 1990. Boston, MA: Massachusetts Department of Public Health.

served in each of its 254 counties. This information is shared with local programs to help them focus their ChildFind efforts.

A closely related application is using data on placements and services to identify local programs that may be relying too much on a particular setting, such as center-based programs. Local service delivery patterns that deviate substantially from other local programs suggest that infants and toddlers and their families may be receiving services based on availability rather than need. Data on the locations where infants and toddlers are receiving services can identify localities that may need assistance in expanding the number of placement options available or being considered.

Data on referrals and referral sources is of interest to a number of states. By examining data on screening, evaluations, and IFSP development, Maine was able to determine that mass screening clinics conducted at the local level were not an efficient use of resources. Although good public relations for the program, screening clinics were costly to conduct and were found to identify few children who required services. The state is now examining alternative approaches to ChildFind. Maine also monitors the number of children referred and the percentage later evaluated and then recommended for service. Minimizing the number of unnecessary referrals or evaluations results in more resources for service delivery.

A particularly powerful piece of data that is collected by several states is number of children on waiting lists[2]. Texas, for example, reported that an average of 439 children were on Early Childhood Intervention program waiting lists in 1989. Waiting list data are also one of the few data elements Congress required states to be able to collect through their data systems.

North Carolina took a comprehensive look at its waiting list in 1990. The state examined the number of unserved and underserved infants and toddlers on December 1, 1990. Underserved infants and toddlers are those who were enrolled in a program but were in need of additional, unavailable services. A total of 2,820 children (1494 unserved and 1326 underserved) were found. By comparing the data for the 1990 with the 1989 data, the state was able to determine that many of the previously un- and under-served children were now receiving the services they needed. North Carolina also looked at the type of service the children needed and the extent of need by programs. Figure 3 shows how North Carolina communicated these data in their report.

One of the most easily observable of the Part H requirements is the timeline. Early intervention programs are required by federal regulations to follow specified timelines for certain events. For example, a program must hold an IFSP meeting

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2 Waiting list data can be a double-edged sword as states move into full implementation. They powerfully demonstrate the extent of the state's need for additional resources, but they also establish the state as out of compliance with federal regulations because not all eligible children are receiving resources.

# Figure 3

## Waiting List Data (NORTH CAROLINA)

**STATEWIDE**

Profiles of Infants/Toddlers on Waiting Lists for Selected
North Carolina Early Intervention Services
December 1, 1990

| I. Selected Services (Duplicated Count of Children) | (Unserved) Waiting for Program Enrollment | (Underserved) Enrolled, Waiting for Other Services | Total |
|---|---|---|---|
| Service Coordination | 1047 | 476 | 1523 |
| Multidisciplinary Eval. | 894 | 537 | 1431 |
| Home-Based | 925 | 565 | 1490 |
| Center-Based Self-Contained | 146 | 303 | 449 |
| Center-Based Therapeutic Preschool | 10 | 23 | 33 |
| Center-Based Mainstreamed | 95 | 283 | 378 |
| Physical Therapy | 271 | 345 | 616 |
| Occupational Therapy | 114 | 295 | 409 |
| Speech/Language | 312 | 481 | 793 |
| Transportation | 184 | 297 | 481 |
| Child Mental Health | 152 | 119 | 271 |
| * Other | 203 | 182 | 385 |
| II. Reporting Program (Unduplicated Count of Children) | | | |
| Early Childhood Interv. | 631 | 435 | 1066 |
| Developmental Day Care | 91 | 265 | 356 |
| Developmental Eval. Ctr. | 380 | 126 | 506 |
| Health Department | 314 | 432 | 746 |
| Child Mental Health | 38 | 24 | 62 |
| ** Other | 35 | 42 | 77 |
| III. Total Number of Children Needing a Service | 1494 | 1326 | 2820 |

* "Other" includes a wide variety of special assessment and services.

** "Other" includes Division TEACCH, Gov. Morehead School, Wake Medical Center, and Raleigh Rehab. Center.

Source: Vandiviere, P., Munn, D., Vitaglione, T., & Sabula, M. (1990). Young Children in Need of Families: A Study of Children in Need of Services, the Services they Require, and Projected Future Needs. Raleigh, NC: N.C. Department of Human Resources.

within 45 days of receiving a referral and the IFSP must be reviewed every 6 months. Ohio obtained federal funding to develop a client- based management information system that collects data on children and families receiving early intervention. Individual client-level data for a subset of the data elements are transmitted from the local program to the state on floppy disks. This data system will provide the state with the capability to monitor the extent to which the timelines are met by providing the dates of various events in the service delivery process for each client.

Planning for the future. For planning purposes, states need to know how many infants and toddlers will require early intervention in the coming years. This is a variation on the question of how many children a jurisdiction should be serving, which has no easy answer. Projecting the size of the population to be served is further complicated by possible changes in eligibility criteria (e.g., inclusion of some groups of children considered to be at risk), changes in the demographic composition of the state, and social problems and new technologies that impact the number of infants and toddlers with disabilities.

One approach to answering this question involves examining data on the number of children served in past years. Data collected over several years provide valuable information on program changes over time and offer some suggestion as to what tomorrow might bring. By looking at early intervention data for the past decade, Texas has documented substantial increases in both the number of programs and the number of children receiving services (see Figure 4). Similarly, Massachusetts' data show a strong growth rate over the past 5 years (see Figure 5).

An alternative approach to projection involves identifying a reasonable figure as the likely percentage of the population to be served in coming years. Additional analyses in the North Carolina waiting list study described earlier produced estimates of the extent of unmet need in the state. The state elected to use 3% as the expected percentage of children to be served in the future. Based on this projection percentage, North Carolina estimated the total number of infants and toddlers in need of various kinds of services. By comparing these figures to the current service delivery capacity, the state was able to project the extent of the need for additional services (see Figure 6).

Forecasts about the nature and size of the population to be served have implications for both preservice and inservice personnel planning. In Ohio, by tracking changes in the kinds of children being serviced by localities (e.g., an increase in the number of ventilator-dependent children), the state can identify areas for inservice training, as well as potential public health problems. Similarly, the state sees the data on the numbers of infants and toddlers with disabilities and their characteristics as important for colleges and universities in developing appropriate training programs. As the population changes, staffing needs change (e.g., need for more occupational therapists) and knowledge and skill needs change.

Figure 4

Trend Data on Number of Children Served (TEXAS)

*10 YEARS OF GROWTH*

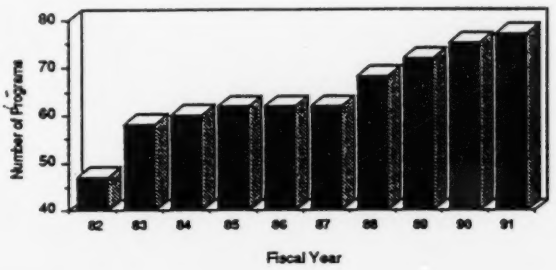
| THEN-FY'82 | NOW-FY'91 |
|---|---|
| 47 COMPREHENSIVE PROGRAMS | 77 COMPREHENSIVE PROGRAMS |
| 150 COUNTIES SERVED | 254 COUNTIES SERVED |
| 2,776 CHILDREN SERVED COMPREHENSIVELY | 9,712 CHILDREN SERVED COMPREHENSIVELY* |
| $6 MILLION BUDGET | $21.4 MILLION BUDGET (projected) |
| 9% of eligible children served | 28% of eligible children served* |

* most recent available data is FY'89

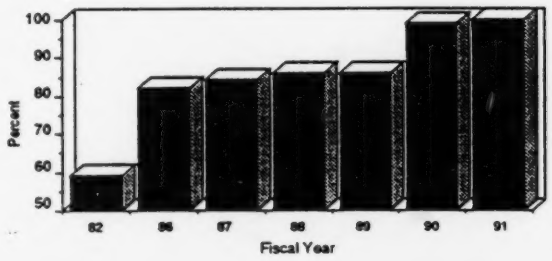
In the past 10 years, the Texas ECI Program has grown dramatically. The ECI council has increased the number of funded programs providing comprehensive services from 47 in FY'82 to 77 in FY'91. Today, programs cover all 254 Texas counties.

The number of families served comprehensively has also increased by approximately 7,000. In FY'82 2,776 children received comprehensive services, that is, they received an array of services as listed in a service plan. In FY'89, the number of children served comprehensively was 9,712.

**From 1983-1985 the methods for counting children were not comparable to the methods used starting in 1986.*

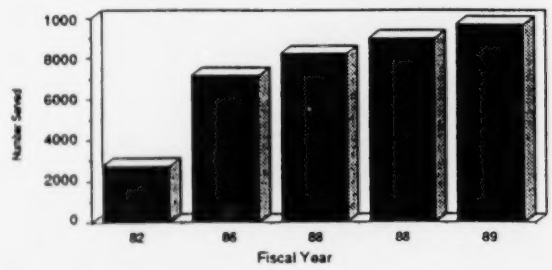



*Number of ECI Programs, FY'82-90*




*Percent of Counties* in Texas Served by ECI Programs*

**there are 254 counties in Texas*




*The Number of Children Comprehensively Served**

**equivalent data unavailable for 1983-85*

Source: The Texas Early Childhood Intervention Program (1990). Helping Families from the Beginning. Austin, TX: Texas Education Agency.

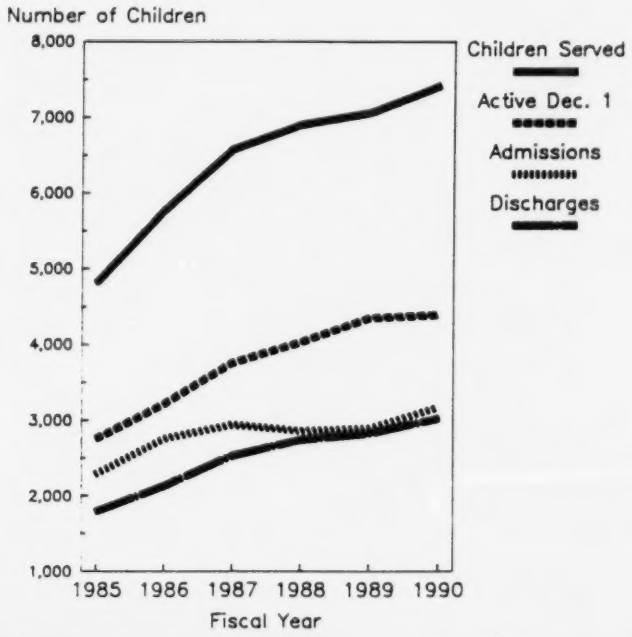
# Figure 5

## Trend Data on Number of Children Served (MASSACHUSETTS)

**Trends in Early Intervention Program Clients**

The number of EIP recipients have clearly expanded since 1985. The number of children served has increased from less than 5,000 in 1985 to over 7,400 children in 1990 (Figure 9). However, as Table 3 demonstrates, the number of children served appears to be increasing at a slower but stable rate from 1987 to 1990.

Figure 9: Children Served by Early Intervention Programs in Fiscal Years 1985 to 1990




| Fiscal Year | 1985 | 1986 | 1987 | 1988 | 1989 | 1990 |
|---|---|---|---|---|---|---|
| Children Served | 4,811 | 5,771 | 6,582 | 6,907 | 7,066 | 7,421 |
| Active Dec. 1 | 2,755 | 3,213 | 3,760 | 4,032 | 4,350 | 4,395 |
| Admissions | 2,289 | 2,756 | 2,942 | 2,856 | 2,893 | 3,169 |
| Discharges | 1,796 | 2,131 | 2,532 | 2,746 | 2,830 | 3,026 |

SOURCE: Early Intervention Program Data, FY 1985-1990, Bureau of Parent, Child, and Adolescent Health, Dept of Public Health

Source: Massachusetts Department of Public Health (1991). Early Intervention Programs: Annual Report, Fiscal Year 1990. Boston, MA: Massachusetts Department of Public Health.

# Figure 6

## Projecting Unmet Need (NORTH CAROLINA)

**REMAINING UNMET NEED**

Finally, current service delivery capacity must be considered against the total in need projections. For selected early intervention services, this comparison would provide the following:

| Service | Total Projected Need | Current Service Delivery Capacity | Total Remaining Need* |
|---|---|---|---|
| Multidisciplinary Evaluations | 6,452 | 3,816 | 2,636 |
| Home-Based Early Intervention | 5,365 | 3,517 | 1,848 |
| Center-Based Early Intervention | 2,642[1] | 2,358[1] | 284 |
| Specialized Therapies | 5,605 | 3,166[2] | 2,439 |

Current service delivery capacity reflects 1989-90 service delivery levels, plus the additional capacity provided through expansion early intervention funds appropriated in 1990 by the General Assembly.

(Figures in this table are not directly comparable to those in the 1989 report because the number of reported children is smaller for 1990.)

*Includes children on the current waiting list.

[1]Developmental Day, Preschools of Division of Services for the Blind and Deaf and Hard of Hearing

[2]Total of 70% of those receiving center or home-based early intervention, minus those enrolled who need but are not receiving specialized therapies

Source: Vandiviere, P., Munn, D., Vitaglione, T., & Sabula, M. (1990). Young Children in Need of Families: A Study of Children in Need of Services, the Services they Require, and Projected Future Needs. Raleigh, NC: N.C. Department of Human Resources.

Building linkages across jurisdictions. One of the many challenges posed by interagency coordination across public and private agencies is that different agencies don't share identical geographical boundaries. Health departments may be regions with one set of boundaries. School districts may have completely different boundaries. Social services may have sub-divided the state in yet a third way. Private institutions, such as hospitals, often have clients from several regions, counties, or school districts. A state-level client-based data system can help facilitate some of the connections across agencies and institutions. A state-level, client-based data system can also track early intervention families who move from one part of the state to another and can help insure that families don't fall through the cracks when they change service areas.

In Ohio, county-level analyses of early intervention are useful to hospitals serving more than one county. The Ohio data base is being developed so that screening results from hospitals can be linked with early intervention enrollment. Every newborn in Ohio receives a hearing screening in the hospital, but referrals from these screenings do not always get linked to an early intervention program. Tracking is particularly difficult when the family is not from the same county as the hospital. Eventually, the data system will be able to track whether or not each referral from a hearing screening turns up in the early intervention system. Referral data will be sent to the state, where they can be checked against the data from the early intervention programs.

Missouri is planning to report to school districts on the number of children who will reach age 3 during the coming year in order to assist the districts in planning for possible enrollments in preschool special education programs. The service areas for early intervention do not correspond to school districts, so the state data base is the only mechanism through which a count of such children can be generated easily for the districts.

Other questions. The number of questions that can be answered by a state data base is limited only by the type and quality of the data themselves. Like Ohio, Colorado received federal funding to develop a client-based management information system. This system was designed with the capability to answer many important questions about the provision of early intervention in the state. Unfortunately, this particular system was not able to secure additional funding when the federal funding ended and is not currently being supported. Nevertheless, the set of questions that the system was being developed to answer are good examples of the potential uses of an early intervention data system and how the need for information can guide its design. CoTrack (1992), the Colorado data system, was designed to provide the state with the answers to the following questions[3]:

1. Are proportionate numbers of each racial/ethnic category represented in Colorado receiving Part H services? Are certain racial/ethnic groups dropping out

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3 The parenthetical comments after some of the questions were included with the questions but were edited by the author.

of the system? At what point? (Information can help pinpoint areas that need to be addressed in terms of cultural sensitivity or areas where finances/transportation, etc., may be a barrier to services among specific groups.)

2. How many children are being screened, evaluated, and receiving services in each school district/county? Are a proportionate number of all children in need of services entering the Part H system in each community?

3. What agencies are doing community screenings? What proportion of children are identified as a result of the community screening process? Is the community screening a cost-effective method of identification?

4. How many children are referred into the Part H system? At what age are infants and toddlers being identified and referred? What is the geographic distribution of referrals? What agencies/individuals are the primary referral sources? What agencies/individuals are not referring children? (Information will be useful to better target public information campaign activities aimed at providers.)

5. What is the frequency of each presenting concern? (The percentage of children presenting specific concerns [e.g., communication delay, cognitive delay] becomes a policy issue as the problem relates to the financing of early intervention services.)

6. How many children are insured with private insurance? Medicaid? Uninsured? What are the policy implications in terms of predicting future Medicaid needs?

7. Are there any children living in a certain area, or whose parents were employed by a specific employer or shared the same occupation, who have similar birth defects or developmental disabilities?

8. How many children in the Part H population have parents with characteristics such as sensory impairment, substance abuse, mental health problems, etc.? What are the implications for care of these children?

9. What is the overall quality of service coordination in Colorado? How many children have a specific, assigned service coordinator? How many contacts does a service coordinator make with a child/family over a given period of time? Are those contacts made by phone, by mail, in the office, or at the child's home? How long is each contact? How does the intensity of service coordination relate to different communities, different funding levels, and different specific disabilities? What kinds of individuals are acting as service coordinators? Professionals? Paraprofessionals? Families? How does the level of service coordination, as viewed from the agency perspective, relate to parent satisfaction as indicated in qualitative survey data?

10. Why are referrals not contacted? How many families were not interested in services? How many families were "no shows"? What were the reasons why children/families did not attend scheduled screenings, evaluations or services?

11. What kinds of actions emanated from each step in the referral process? For example, how many children were referred from a community screen into an evaluation? a repeat community screen? community services? tracking? How many children were evaluated and referred to services? IFSP? How many children were evaluated and determined to be in need of early intervention services who are not receiving those services? Why? Where are children and families being referred who may not be eligible for Part H services but would benefit from some kind of early intervention activity?

12. What funding sources are being used to support evaluations? Services? How many services are being reimbursed at rates below actual cost? What is the differential?

13. How often were children referred to early intervention services in their community that were not entirely appropriate for their needs? Are there children with specific kinds of disabilities who are not receiving appropriate services? How does this problem translate to policy and funding issues? Are parents forced to travel long distances to provide their children with early intervention services? Can we create some alternative local service provision arrangements?

14. How many children in the state are receiving each category of early intervention service? What kinds of service environments are being utilized for what kinds of services and disabilities?

15. How often are the parents and family being utilized as a resource for responding to the child's needs?

16. What kinds of services and supports are families requesting information about on the Family Interest Survey in each community? Do certain services need to be publicized more aggressively on a state-wide basis? How are community services being used in conjunction with early intervention services?

17. Is the best transition alternative available for each family within their own community? Are preschool providers being included in the transition process?

18. How is early intervention working in Colorado? (Eventually combining the CoTrack database with data collected by the Colorado Department of Education should yield a wealth of information on the results of early intervention efforts.)

Sharing data with legislators. States are using their data systems to provide many different kinds of information about early intervention. Several of the states in the study noted the importance of providing early intervention data to their state legislatures. Texas, for example, produces quarterly reports for the legislature. In Massachusetts, data played an important role in getting legislation relating to the use of third party payments for early intervention services. Additional dollars were appropriated for early intervention in North Carolina after the data on unserved and underserved were shared with the legislature. Both Ohio and North Carolina produce data reports for individual legislators. These states indicate that the

individual district reports have been "tremendously powerful" in helping legislators understand the need for early intervention.

Billing for Services

Paying for early intervention will never be easy. Even if we put aside the challenge of acquiring funding, there remains the operational challenge of how to disburse funds across a system of public and private service providers. Automation represents one way to streamline the process of reimbursing those who provide early intervention services.

The Missouri MoCares data system is being designed to manage the billing and reimbursement process for children whose services are being coordinated through the Missouri Department of Health. Under this system, state-approved service providers will bill the state Department of Health for early intervention services they have provided to children and families. These bills will be entered into the computer ,which will verify the claim against the IFSP that is already in the data base. The program will check to make sure the service and service provider are part of the child's IFSP. If the claim is verified, the claim will be paid.

Currently in Missouri, only the IFSP information is in the data base. State staff determine the legitimacy of each claim submitted by pulling up the service plan on the screen. State staff hope to cut the amount of labor currently necessary and the reimbursement time (down to 28 days from the 45 to 90 days it is now taking) by automating the billing process.

Ultimately, this system could be broadened to include not just services paid for by the Missouri Department of Health, but by other payors as well. This innovation would replace the present system under which a service provider must make a determination as to which entity (e.g., Department of Health, Medicaid, private insurance) should be billed for the service. The Department of Health would reimburse the service provider and then be reimbursed through automatic transfer of funds across state accounts.

Several unique features of the MoCares system permit the automation of the billing process. First, the state data base contains personally identifiable information on clients and their services. Second, the state agencies have developed interagency data sharing agreements that provide for access to information from other agencies on a "need to know" basis. Missouri state staff maintain that using a common client number and linking data across agencies facilitate eligibility determinations for multiple programs and improve service coordination.

Meeting Federal Reporting Requirements

One state-level use of the data system shared by all states is the submission of the data on early intervention required by the federal government. To receive federal funding through the Part H program, the lead agency must agree to submit the data required by the U.S. Department of Education. Five types of counts were requested in 1992: an unduplicated count of children served, the number awaiting

service, types of services provided, type of personnel employed and needed, and setting in which children receive service. The Department of Education reports the data submitted by states to Congress in its Annual Report on the Implementation of the Individuals with Disabilities Education Act. These data, which constitute the only national data bases on early intervention, are also used by professional associations and advocacy groups (Hebbeler, 1991).

All states share the requirement to submit data to the Department of Education, but states differ dramatically with regards to gathering and organizing the data to meet those federal requirements and the problems they have encountered. States provide the federally required data by analyzing one or more data bases containing data on infants and toddlers, surveying programs, or both. This section will describe the differing approaches of three states: Texas, which surveys programs to get their data; Maryland, which has created an information management system for local programs that also provides data to the state for the federal reporting requirements; and North Carolina, which merges data across several state-level data bases to produce the federally required data on early intervention. Each of the approaches has been, more or less, successful.

I would not, however, want to create the impression that *all* states have been as successful as these three states. Both my experience at the Department of Education and my ongoing work with the data submitted by states strongly suggest that a number of states still have not developed an approach that will produce valid data on the counts requested by the Department of Education. (Many of these states can't produce other data either, but it is the federal reporting requirements that annually expose the shortcomings of the early intervention data system.)

The barriers to the valid collection of data for the federal reporting requirements take many forms. At one extreme are states that provide early intervention through several agencies with a long history of service delivery and data collection. Neither the service system nor the data system were designed exclusively for birth through 2-year-olds. Altering pre-existing systems to provide new data can be time-consuming and resource-intensive, especially if the new requirements impact only a small percentage of the clients in the data base (i.e, those 2 years of age and under). The technical challenge involved in getting independent data systems to communicate with one another is surpassed, however, by the administrative challenge of working out the necessary interagency agreements to allow data sharing in the first place. At the other extreme are states trying to build a service delivery capacity. The data system in these states is no less developed than any other aspect of service delivery, but all aspects are in need of additional time and resources.

Acknowledging the variation in state capacity to comply with the federal reporting requirements, the discussion will now focus on three approaches (the approaches used by Texas, Maryland, and North Carolina) that are successfully producing the required data.

Surveying Programs (Texas)

The provision of early intervention services in Texas is organized around 77 local programs. The state funds each of these local programs through a competitive bidding process. The state's data system is based on a variety of paper surveys of these 77 local programs. In response to the federal reporting requirements, Texas developed another survey to provide the federally requested data. The survey approach works in Texas because of the way the early intervention system is organized and because the lead agency funds the local programs. The universe of local entities to be surveyed is known to the lead agency and the lead agency has sufficient authority to request the information it needs.

The new survey developed for the federal reporting requirements is called the Once-a-Year Survey and consists of three data tables that local programs must submit on December 30. Texas re-worked the federal data tables and the instructions to make them more suitable for the respondents. The completed surveys are entered into a data base and analyzed at the state level.

Federally-requested data on the number of personnel employed and needed are submitted by local programs in their annual proposal to the state for funding. Texas requires a number of additional data elements on personnel besides the federal requirements such as salary and certification. The personnel data are not just submitted to the federal government; they are used by state fiscal and programmatic staff in oversight and planning activities and by other state and local agencies in planning activities.

Extracting from a Management Information System (Maryland)

Maryland takes a very different approach to the federal reporting requirements. The early intervention system in Maryland is county-based, with three public agencies and numerous private providers involved in the provision of service. At the local level, there is a single point of entry to the system. The data system, designed by the state for the local programs, was engineered to be a child-based management information system for local program operation, but it also includes the necessary data elements to satisfy three of the four federal reporting requirements. Periodically, data are entered by local jurisdictions with data sent to the state on floppies. Data from the local programs are analyzed at the state level to produce the federal data reports. The only exception to this process is the report on personnel. Personnel data are collected by paper surveys of the local programs.

Several features of the Maryland system appear to contribute to the state's success in meeting the federal reporting requirements. First, the management information system was designed to provide the necessary information to meet the federal requirements. Second, the data system provides direct benefit to local programs, so there are strong incentives to input the data and keep them current. Third, Maryland invested and continues to invest in supporting the use of the system through technical assistance available from the lead agency. Not only do

local staff have sufficient incentives to use the data system; they have been provided the necessary assistance to be able to use it.

Linking State Data Bases (North Carolina)

North Carolina uses a third approach to the federal reporting requirements, one that involves electronic linking of data from several data bases. Early intervention services in North Carolina are provided by several agencies that have their own structures for service delivery at the local level. The major state agencies providing early intervention in the state each had well-established data systems prior to Part H. Through modification of the data being collected and through the creation of a common identifier, the state was able to create a data set that produces the information needed for the federal reporting requirements.

One of the key problems faced by states with multiple data systems is the inability to produce an unduplicated count of children served. Each data set produces a count, but there is no way to know how many children are in more than one count. To provide an unduplicated count of infants and toddlers, the North Carolina data tapes from the individual agencies are merged through the use of a common identifier (first three letters of the last name, first letter of the first name, birth date) with names removed. This creates a new data set consisting of all children served, with duplicate records removed. To provide the federally-required data on services and setting, the Part H agencies have agreed to utilize a common set of data forms for children receiving early intervention. These forms are being used by the local programs, making the necessary data elements available at the state level when the merged data set is created. Like Texas and Maryland, North Carolina collects the personnel data by surveying programs.

The complexities in the service delivery system in North Carolina would appear on the surface to make data collection considerably more difficult than in either Texas or Maryland. The state's approach works because the agencies involved were able to agree on a common goal and to undertake the steps necessary to achieve it. The North Carolina experience is important in illustrating that a comprehensive state-level early intervention data system can be created even in states with multiple data systems.

State agencies use their data systems for many purposes, including overseeing service provision at the local level, billing for services, and providing the federally required data. Local programs also have a variety of ways to use their data systems.

## Use of a Data System by Local Programs

Local programs can benefit from much of the same information as that needed by state agencies. Descriptive data about various aspects of program operation assist local program administrators in managing, evaluating, and planning for the future. Like their state counterparts, local program managers are interested in the characteristics of their population, in how these are changing over time, and in the sources of referrals.

Local early intervention programs also have other uses for data systems. In many states, local programs face a management information challenge greater than that faced by the state agency. Where the state tracks program-level information for 25, 50, or 75 local programs, the local program may be managing the records of 500 or more infants and toddlers. The computer's capability to store, manipulate, and provide access to individual or sub-sets of records can make an especially valuable contribution to the operation of local programs.

This section of the report describes some of the features of the early intervention data system in three states. In each of these states, one of the primary objectives for the data system was to assist local program management. A review of the early intervention data systems developed in Maryland, Colorado, and Ohio identified a number of capabilities being built into their systems for local use. With these data systems, local programs can do some or all of the following:

- generate statistical reports on clients for planning and evaluation purposes
- review data and produce various lists or sub-sets of children
- monitor the status of services to individual children and families (e.g., "tickler systems" that remind about upcoming dates)
- produce legible, complete copies of a child's record, including the IFSP for sharing with the family, other staff, and other community agencies
- access information about other resources available in the community
- generate individual transition reports for school districts that will be receiving the program's 3 year olds
- easily and quickly transmit required data to the state
- word process and produce labels for mailing or file folders

To enable these activities to occur, the necessary data elements must be in the local program's data base. Certain core data elements appear across many early intervention data systems. The systems differ in how much and what type of information they collect beyond the core. The systems designed for local use recognize that not all local programs may be interested in all the possible data elements programmed into the system. States have earmarked certain elements (e.g., those required to generate the state data reports for the federal government) as mandated. The decision to collect and enter data on the others is left to the local programs. Locals also can adapt the system to their needs by adding their own data elements either in the form of individual customized data fields or through "comment" fields, which are available for entering text (e.g., notes about a child). Table 1 shows a listing of data elements being collected by Maryland, Colorado, and/or Ohio.

## Table 1

**Examples of Data Elements in Systems Designed for Local Use**

**Child** (name, address, date of birth, gender*, race/ethnicity, social security number, identification number)

**Family** (parent/caregiver name, address, age, race/ethnicity, marital status, language)

**Emergency contacts**

**Consent for release of information**

**Health** (hospital*, immunizations)

**Payment** (insurance, Medicaid number, payment source)

**Referral** (date, source)

**Screening** (date, agency, outcome)

**Evaluation** (date, agency, outcome)

**Service Coordinator** (name, agency, phone)

**Child status** (active/inactive, delayed/at risk, category, eligibility)

**IFSP** (date, strengths, needs, goals/objectives, services)

**Services** (date of entry, type, amount, provider)

**Non-IFSP Services** (prior or current)

**Comments, additional information**

**Community Resources**

**Transition** (school district*, services, resources)

* To facilitate data entry, systems often include in the data base a list of possible data choices from which the user makes a selection. This list may be short (e.g., gender) or rather lengthy (e.g., agencies, hospitals, school districts).

Generating Reports and Lists

Developers of data systems use the word "report" to refer to a variety of outputs. These span the gamut from aggregated information about all the children in a program (e.g., 68% of the children are male) to the complete record for an individual child. The computer's capability to produce such reports with so little effort is one of the obvious advantages of a data system. For discussion purposes, I will refer to aggregated information as a "report," to listings of individual children as "lists," and to information on an individual child as an "individual record."

As mentioned above, local program managers use aggregated information about the children in their program in much the same way state administrators do: to describe their population for internal and external use, to monitor program operation, to track trends and plan for the future. When utilized effectively, these reports allow the local program staff to make decisions from an informed perspective. Reports on local programs are available even in states where the early intervention system was not designed for local information management. The state agencies in Massachusetts and Texas, for example, produce reports for the local programs from the state data base.

The advantage for local programs that maintain their own data bases is that they can manipulate their data themselves. Given sufficient technical expertise, they can raise and answer many questions about their program. The states have anticipated local needs by designing the data system to produce a standard set of reports with the option to produce customized reports as needed with only a minimal number of additional steps. The Maryland data system allows the user to go one step farther and display the report data in a variety of graphs such as pie charts or bar graphs.

Sufficient technical expertise and a high comfort level with the data system are critically important to its usefulness at the local level. The state agencies designed these systems to have many capabilities and yet be user friendly. The full potential of the system can only be realized, however, where local staff have the knowledge, inclination, and time to utilize the system's capabilities. A reasonable hypothesis would be that substantial variation exists at the local level in the extent to which data systems are being used with some local staff being more favorably disposed to utilize the full capabilities of the system.

While aggregated information is useful for reporting purposes, lists of children are tremendously beneficial to day-to-day program operation. Which children and families have Sarah R. for their service coordinator? Which children will turn 3 in the next 6 months? Whose IFSP needs to be reviewed before May? All of these questions and many more can be answered by a data system. The Maryland system, for example, produces rosters of children showing names, date of birth, category (delayed/at risk/new), status (active/inactive), social security number, gender and identification number (see Figure 7). The "search and sort" feature allows the lists to be re-arranged and/or sub-divided at will -- in alphabetical order or from oldest to youngest, showing only children who are in the "active" status or who are developmentally delayed, etc.

Figure 7

Sample List of Children (MARYLAND)

**Maryland Infants and Toddlers Tracking/Data Collection System**

# The Children Window

File Edit Enter Select Report Special Child 7:27

**Children: 30 of 30**

| Last Name, First, Middle | Birth Date | Category | Status | SSN | Gender | Index# |
|---|---|---|---|---|---|---|
| Andrews, Susan L | 3/25/90 | Delayed | Active | | Female | 67 |
| Barker, Bruce C | 12/15/91 | New Child | Active | 222-45-6321 | Male | 4 |
| Brown, James A | 2/8/90 | Delayed | Active | 236-51-4618 | Male | 28 |
| Brown, Jamie A | 7/2/91 | Delayed | Active | 218-32-4521 | Female | 24 |
| Chavez, Emilio R | 4/5/90 | Delayed | Active | | Male | 58 |
| Croxton, Greta S | 11/15/91 | New Child | Active | 212-22-1231 | Female | 65 |
| Fallstaff, Kira F | 11/25/91 | At Risk | Active | 222-78-7877 | Female | 5 |
| Fisher, Helen M | 8/25/88 | New Child | Inactive- | | Female | 37 |
| Garrison, Timothy J | 11/8/89 | Delayed | Active | 231-56-8976 | Male | 32 |
| Harris, Tina M | 3/1/89 | Delayed | Inactive- | | Female | 31 |
| Harrison, David J | 1/4/92 | New Child | Active | | Male | 38 |
| House, Mona B | 1/11/89 | At Risk | Inactive- | | Female | 2 |
| Johnson, Maurice J | 4/23/90 | New Child | Active | | Male | 61 |
| Jones, Bryan T | 2/14/90 | Delayed | Active | 237-52-8632 | Male | 35 |
| Jones, Jane J | 8/4/90 | Delayed | Active | | Female | 59 |
| Jones, Tanya J | 12/19/91 | Delayed | Active | | Female | 36 |

Done

Source: Maryland Infants and Toddlers Program (1991). Procedures Guide for the Maryland Infants and Toddlers Program. Baltimore, MD: Maryland Infants and Toddlers Program.

Tracking Service Provision

An often voiced complaint about human services is the problem of "falling through the cracks." A data system won't forget, lose records, or get bogged down with too many other competing priorities. Provided someone asks the question, the system will be ever ready to remind the user about upcoming events. The reminder capability, commonly referred to as a "tickler system," is one important way the computer can enhance the overloaded information processing capability of local program staff.

One type of tickler system is the production of lists as described above. Several key aspects of service delivery of service provision under Part H are tied to dates. Data systems can easily produce lists of children and families who will need IFSPs reviewed next month or for whom transition services should be planned.

The Colorado data system contains a specialized type of reminder system. This feature was designed to maintain temporary information and print reminders to individual staff or a group of staff about upcoming events or individual meetings. The tickler system operates as an ongoing electronic "to do" list, incorporating information already in the data base. For example, a service coordinator could create a report showing all children for whom she needs to make a follow-up call regarding a screening referral between March 1, 1992, and March 31, 1992. Other upcoming events such as meetings already entered in the system would automatically be part of the tickler report. Figure 8 shows an example of a tickler report from the Colorado data system.

Information Sharing

Part of the legislative rationale undergirding Part H was the need for coordinated services to young children and their families. A key aspect of coordination is the selective sharing of information across individuals and agencies. When used effectively, early intervention data systems can provide multiple service providers ready access to the same information about a family. This information can be basic demographic or personal data (e.g., the Colorado system includes directions to the family home) or case notes that are entered through a "comment" feature. Confidentiality issues are always a concern when information is shared, but the general assumption is that information sharing, combined with the proper safeguards to protect confidentiality, is beneficial to the family. An obvious benefit is that families need not spend hours of their time providing the same information to different agencies or individuals. A benefit more difficult to observe would be the increase in the quality of the service presumed to occur when a service provider has ready access to all the necessary information concerning a child and family.

Families are recipients as well as contributors to information from early intervention program; they too can benefit in a number of ways from an early intervention data system. Besides saving a family's time with regard to the collection of data, a data system can produce a current, complete, organized, legible record of information about their child. Information in file folders can always

Figure 8

Tickler Report (COLORADO)

TICKLER REPORT
Printed: 02/27/1992, 03:59:09

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From: 01/02/1992
To: 01/01/1993
Staff: JS JANE SMITH

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| | | |
|---|---|---|
| 03/01/1992 | Date Entered: | 02/27/1992 |
| | Tickler Category: | 01 SCREENINGS |
| | Staff: | JS JANE SMITH |
| | Local ID: | 1, JOHN ROGER DOE, 08/03/1988 |
| | Description: | F-U ON SCREEN RESULTS |
| | Contact: | Pat Jones |
| | Phone: | (303) 999-9999 |
| 03/23/1992 | Date Entered: | 02/13/1992 |
| | Tickler Category: | 01 SCREENINGS |
| | Staff: | JS JANE SMITH |
| | Local ID: | 2, SARAH ANN PATTERSON, 12/20/1990 |
| | Description: | F-U ON SCREENING REFERRAL |
| | Contact: | Denver IACT |
| | Phone: | (303)333-3333 |
| 03/24/1992 | Date Entered: | 02/24/1992 |
| | Tickler Category: | 04 MEETINGS |
| | Staff: | JS JANE SMITH |
| | Description: | ATTEND HEADSTART - 9:00 AM |
| | Contact: | 1600 Broadway |

Source: Kahn, V., Kelley, J.E., & Unger, C.B. (1992). CoTrack Information Management System Reference Manual. Denver, CO: Colorado Department of Health.

be copied, but the usability of the information may be somewhat variable. And while some may feel a computerized record of the IFSP is depersonalized, others may appreciate that it is a lot easier to read than the fourth copy from self-carboning paper. Like program managers and service providers, families are decision-makers and can benefit from ready access to the relevant information available on their child.

The Policy and Procedures Guide for the Ohio data system summarizes the benefits of a data system to families. A data system:

- facilitates the delivery of coordinated services based on accurate record of services being provided by all involved agencies
- provides a mechanism for furnishing parents with information on their children, such as referrals made, evaluations completed, and IFSP timelines for the purpose of participating in decisions concerning service delivery options and transition decisions
- assists families and service coordinators in developing and monitoring IFSPs through improved efficiency in data management (Ohio Department of Health, 1991)

Linking to Community Resources

Many jurisdictions have recognized the computer's utility for creation and storage of the central directory required by Part H. Connecting this type of directory to an individual client data base represents a next step in the maximum utilization of the computer. Colorado's plan for its data system included a linkage with a directory of resources available in the community. The Colorado user could query the directory through a number of different variables such as service or service area. Agency addresses could be used to create mailing labels and letters.

Transition

The child and family's transition out of the early intervention program at age 3 can be aided by several of the data systems features discussed above, such as the production of lists. In addition, each of the three states studied has developed specialized features in their data system for transition.

The Maryland system's transition information includes whether or not the child will require Part B services and a list of the additional resources planned for the child. Space is provided to enter more information about each of the resources. The Colorado system records the date of transition, appropriate preschool options and their availability, the final placement decision, steps to facilitate transition, the date, name, and address for a letter to the preschool program. The Ohio system produces a specialized transition report for the receiving program that includes basic demographic information, the school district, the service coordinator's name and agency, dates of entry and exit into early intervention, program setting and the

text of the IFSP. Ohio notes that the report assists schools and programs in making the necessary preparations for the children they will be receiving.

Submitting Required Data to the State

In addition to meeting local information management needs, each of the three locally-focused systems was designed to be able to produce required data for the lead agency. Each system includes the necessary data elements in the data base as well as a procedure for extracting these data so they can be sent from the local level to the state. Each system has a simple routine that allows the local user to produce a floppy disk containing a subset of data elements from the local data base. This floppy is mailed to the state agency, which then conducts the analyses to produce information for the federal reporting requirements as well as for their own purposes. Each state receives individual child level data that allows the state to create a child-level (versus program-level) data base.

Office Automation

Through the contributions of computers, states have enhanced the standard office automation capabilities by designing data bases that allow child and family information to be inserted into documents. By building word processing and label generation capabilities into their data systems, states have provided local programs with a time-saving device that promotes communication with families and other agencies. Standard form letters (e.g, notifications) make up much of the written communication from early intervention programs. Information such as dates and names and addresses of families and agencies can be easily inserted into a previously created letter that has been already entered into the system. By marrying word processing with data base information, the data system can save valuable staff time and produce a letter containing as much information as necessary.

These three states (Maryland, Colorado, and Ohio) have developed data systems that apply the computer's capability to early intervention in varied and creative ways. Whether the task is generating a list of children, a transition report, or a mailing label, these data systems can contribute to program operation at the local level.

## Summary and Recommendations

Congress crafted Part H to accommodate the wide diversity across states. While stipulating general requirements that must be met, the legislation also provided great latitude for early intervention systems development. As we have seen, the state response to the requirement to establish a data system has taken many forms. States have elected to ask their data systems to perform many different functions that meet state (and through the states, federal) and/or local needs for information.

The overview of state data systems described how state systems differ across many dimensions. These include: the level of governance (local, state, federal) for which the system was designed to provide information, the kinds of data

being collected, the point in the information flow at which data are computerized, how data are transferred from the local level to the state, the level of data available at the state, the type of reports generated from the data, the nature of the relationship between state agencies and local programs, the capability of the system to address the federal reporting requirements, and the number of data systems operating in the state.

The review of uses of early intervention data at the state level described how states are using data to oversee local programs, to bill for services, and to respond to the federal reporting requirements. In carrying out their oversight responsibilities, state agencies are using early intervention data to describe whom they are servicing and the services being provided, to identify weaknesses in the service delivery system, to plan for the future, to build linkages across jurisdictions, and to answer a variety of questions about early intervention in the state. Lead agencies are also sharing data with state legislatures to help them understand the need for early intervention.

The review discusses many of the uses to which data are put at the state level, and their corresponding use at the local level. In addition, local programs are using management information systems to improve the delivery of service by generating statistical reports on their clients, producing lists of children or subsets of children organized in a variety of ways, monitoring the status of services to individual children and families by, for example, providing a reminder about a required upcoming event on the Part H timeline, producing copies of a child's record including the IFSP, providing links to information about other resources in the community, generating transition-related information for school districts that will be receiving the program's 3 year olds, transmitting data to the state, and automating routine clerical functions such as generation of letters or labels.

This report has intentionally focused on states that have or are planning to have data systems with the capacity to serve unique purposes, multiple purposes, or both. These states are not representative of the nation and what they are doing may not characterize other states. In fact, a number of the other states are in a much earlier stage of data system development. They don't have a system or have too many systems to even be able to report such basic information as how many infants and toddlers are receiving early intervention in the state. State data systems, like every other component of early intervention systems, vary on every imaginable dimension. The objective of this report was to describe some of the possible functions of a data system in early intervention but the possible is probably not typical.

This report portrays data systems as powerful tools for those delivering and managing the provision of early intervention systems. Unfortunately, the potential of this particular tool cannot be realized without a sizeable and ongoing investment of resources. If funding is provided but inadequate, resulting in poorly written manuals or insufficient technical support, the investment may be totally wasted. Those states or local programs in the initial stages of data system development will discover that the road to a completely operational data system has many obstacles. Financial commitments to the system may come and go. The design of the system may take several forms as administrators come and go. Contractors may charge

too much, produce too little, or both. Staff resistance at all levels may seem never-ending. Yet many states with current or emerging data systems will verify that these obstacles can be overcome.

Although it might be nice to conclude with a recommendation for one type of data system or one set of functions all data systems should perform, the needs across and within states are simply too varied. Each state must reflect on its own need for information when developing a data system that will be a useful tool in building and improving state-wide early intervention systems. Recommendations of a more global nature, deriving from this study, include:

**1. An early intervention data system should be driven by information needs of state and/or local staff.**

This rather obvious recommendation has served as the basis for this report. As obvious as the recommendation may appear, it has its origins in conversations I have had with state staff whose data systems appeared to be driven solely by the federal reporting requirements or by a data system developer who was unfamiliar with early intervention. Furthermore, states should start with the purposes they want the data system to achieve or the questions they want it to answer. Presumably, other uses for the data will emerge with time, but concentrating on the data elements themselves almost guarantees two unfortunate results. The first is that answers to key questions that could have been obtained with a better conceptualized system will not be available because the necessary data were not collected. The second is that energies will be expended collecting, entering, and analyzing data elements that no one will ever use. Identifying up front all the possible ways in which information could improve the provision of early intervention is not an easy task but it is a lot easier and far more cost effective than revamping a data system that isn't meeting important state or local needs for information. Collectively across the nation much good thinking has already been done, as exemplified by the eight states highlighted in this study.

**2. States need to create an "information culture" to enable data systems to benefit service provision.**

Data systems don't convert data to information; people do. The people who interact with the data system by providing, receiving, analyzing, or interpreting the data have the capability to either increase or decrease its value. State agencies have many ways of communicating the message that the data provided by local programs are important. The data are shared with those who provided them. The data are graphed and tabled and communicated to state officials or the public on a regular basis. The data are reviewed and checked for inconsistencies. Ongoing technical assistance is provided to develop the necessary capabilities of local program staff. Decisions are based on information provided through the data system and the data suppliers are aware of the basis for those decisions. The value of the data is expressed in many ways in an information culture.

Alternatively, data can be devalued by those who interact with the data system. Local staff can be given the impression that they are submitting their data into a "black hole" at the state agency, future destination unknown. Data

requestors at the state or local level can request data in a perfunctory manner making it clear that they neither know nor care why the data are being collected. Data suppliers rarely if ever receive feedback or reports based on what was submitted. Decisions are often made in the absence of data and without any attempts to obtain any. Congress required that states develop a data system as part of their early intervention system but no one said they had to like it.

These are the two extremes of an information culture. In reality, no state is probably as information-friendly or as information-aversive as the extremes. Any state that is interested in using information to improve early intervention services must concern itself with more than hardware and software issues. The extent to which a culture has been created that supports the production and utilization of data will ultimately determine the worth of the data system.

**3. States need to utilize a variety of approaches to obtain the information they need.**

Most of the states examined as part of this study were using more than one way to collect the information they needed. Many had a client-level data base that provided much crucial information on early intervention, but this data base was supplemented by other data collections as well. Not all information, such as personnel information, is tied to individual children, so alternative approaches may be more appropriate. The answers to some types of questions can be successfully obtained without collecting data on every single child in early intervention. Texas successfully surveys a sample of children and families to learn about the demographic composition of families in early intervention and to examine family satisfaction with the program. Surveys also provide the flexibility to explore significant issues which emerge after a management information system has been developed and implemented. Some data, especially if they are very costly to collect, may only need to be collected biennially or even less frequently. States may be able to realize substantial efficiencies in their data collections if they don't try to answer all questions through a single data system but rather develop a variety of approaches tailored uniquely to the information needed.

**4. States need to maintain a balanced perspective about the amount of error in the data they collect.**

I have noticed an unfortunate tendency to completely disregard data that contain some degree of error. Although perfection is a great goal, in the real world it is usually not possible. It may not even be desirable if substantial human or resource costs attach to achieving added precision, which is sometimes not necessary for decision-making. The value of knowing that 2% of the state's population is being served in early intervention may not lessen if the "true number" is actually 1.5 or 2.8%. The 2% figure almost certainly suggests that the "true" number is not likely to be 15%, which may be all a state needs to know at a certain point in time for certain kinds of decisions. While data that are 100% accurate are obviously the ideal, approximations are often a good start to building an information culture; belittling whatever data are available may ultimately be counterproductive.

The varied and innovative uses of data systems documented in this report constitute a body of evidence that the investment in a data systems has the potential to ultimately add rather than subtract from the limited pool of resources available for early intervention. By exploiting the power of information and the computer's power to manipulate it, some states have found ways to increase the efficiency and effectiveness of their early intervention system. In these times of tight budgets, many states are being asked to serve more families without substantially more money. A well-conceptualized and implemented data system can free staff from tasks the computer can do and allow the staff to spend more of their work hours doing things that only people can do.

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# APPENDIX A

## State Capsules

State Capsule: **COLORADO**

**The State:**

Population: 3,294,394 (Rank: 26)

Size: 103,730 square miles (Rank: 8)

Number of counties: 63

**The Early Intervention System**

Lead Agency: Department of Education

Number of infants and toddlers receiving early intervention on December 1, 1991: 2,547 (1.64%)

The Departments of Health, Institutions, Social Services, and Education are participating in the early intervention system. The early intervention system is based on a set of values that include providing choices of services to families and utilizing existing resources in ways that allow for individual community differences. To build the capacity of local communities, the lead agency allocates funds to the community based on its percentage of births. (A community is a county or group of counties.) Services are provided by a variety of public agencies and private providers.

**The Data System**

Name: CoTrack Information Management System

Cotrack was developed through a grant from the Office of Special Education Programs. This IBM-compatible database program was designed to be used by local service coordinators. It creates a fully automated service coordination record for each family and child. The database stores information on the child and family, medical/developmental history, services, and progress. It generates a set of reports designed for program evaluation and to fulfill the data reporting requirements for specific programs such as Part H and the Colorado Department of Health Diagnosis and Evaluation Program. Agencies can elect to use different portions of the program. An additional module to be used by health agencies was developed with support from the Colorado Department of Health. Funds were not available to support continued development and technical assistance for the system at the end of the grant period so it is unlikely the system will be used state-wide.

State Capsule: **MAINE**

**The State:**

Population: 1,227,928 (Rank: 38)

Size: 33,265 square miles (Rank: 39)

Number of counties: 16

**The Early Intervention System**

Program Name: Child Development Services

Lead Agency: Interdepartmental Council

Number of infants and toddlers receiving early intervention on December 1, 1991: 653 (1.28%)

Early intervention services are governed and managed at the state level by the Interdepartmental Council (IDC) under the Interdepartmental Council on Early Intervention which was established in state statute. Agencies involved include the Departments of Education and Cultural Services, Mental Health and Retardation, and Human Services. The interdepartmental governance structure is replicated at each of sixteen sites by the Regional Boards. Services are provided through an interagency/public/private partnership encompassing Public Health Nursing, the Bureau of Children with Special Needs, Head Start, privately operated day care and nursery school programs, community health programs, private, non-profit agencies providing services such as mental health counseling, physical therapy, hospitals, and private clinicians in the fields of mental health, speech, language and audiological services, etc. Families enter the system through the local program sites who contract with programs or private providers for early intervention services.

**The Data System**

Name: Maine Early Intervention Data System (MEIDS)

A previous data system is being replaced by a new data system being developed for Child Development Services. When fully operational, the system will track records of children ages birth through five years served at each of the local program sites. Data are entered and maintained by an administrative assistant at each site. The data system maintains individual client data on screenings, evaluations, and services. The system also maintains data on cost of services and who is paying for the service (e.g., the program, Medicaid, private insurance). The system will have the capability to generate a variety of reports including quarterly reports for the state. The state report contains aggregated information from the local programs. Local programs had previously transferred information via hard copy and floppy disks but are now linked to the state by modems.

State Capsule:

# MARYLAND

**The State:**

Population: 4,781,468 (Rank: 19)

Size: 10,460 square miles (Rank: 42)

Number of counties: 23

**The Early Intervention System**

Program Name: The Maryland Infants and Toddlers Program

Lead Agency: Governor's Office of Children and Youth

Number of infants and toddlers receiving early intervention on December 1, 1991: 2,775 (1.20%)

Three state agencies are participating in the provision of early intervention services in Maryland: the State Department of Education, the Department of Human Resources, and the Department of Health and Mental Hygiene. Services are provided by these three agencies plus private providers, Interagency Coordinating Councils have been established in each of the 24 local jurisdictions in the state (23 counties and Baltimore City) and local lead agencies have been designated. Specific features of the early intervention system include a single point of entry, trans-agency case management, service delivered within community-based system, services delivered on a year round basis, and services financed through a combination of public/private payments.

**The Data System**

Name: Infants and Toddlers Tracking/Data Collection System

The data system is a child-based information management system which allows local jurisdictions to keep track of pertinent information about each child and family's participation in the early intervention system from referral to transition and to submit accurate data to the state. It is a MacIntosh-based system which was developed as part of the implementation of the Part H program. The state provided the local jurisdictions with hardware, software, and training in use of the system. Types of data entered include basic identification information, referral information, developmental risk factors, and IFSP-related information. Local jurisdictions are responsible for developing a process for flow of data from the single-point of entry and the service coordinators to the local data collection system, performing or monitoring data entry, and submitting reports to the state. Data are transmitted to the state on diskettes with child's name removed.

State Capsule:

# MASSACHUSETTS

**The State:**

Population: 6,016,425 (Rank: 13)

Size: 8,284 square miles (Rank: 45)

Number of counties: 14

**The Early Intervention System**

Program Name: Early Intervention

Lead Agency: Public Health

Number of infants and toddlers receiving early intervention on December 1, 1991: 5,549 (2.09%)

The Department of Public Health awards funds through a request for proposals to 49 local early intervention programs. These programs are operated by a variety of public and private agencies such as mental health organizations or hospitals. Each local program is community-based serving several neighborhoods. The number of children served in a local program ranges from about 50 to 250 children. Local programs are staffed by a team made of professionals from a variety of disciplines. Services are funded by a variety of sources including private insurance.

**The Data System**

Name: Early Intervention Data System

The state-operated early intervention data system, like the early intervention system, was developed prior to the passage of P.L. 99-457. Local programs send the state a paper copy of a registration form for each new child at program entry. Children are coded by a numeric identifier with names stored at the local program. Programs also send the state a discharge form when a child exits the program. Included on the registration form are sociodemographic, referral, medical and functional information. The state generates standard local, regional and state reports from the data base every six months. In addition, special reports can be requested. Information from the data base is also shared in an Annual Report. A separate data base includes information about services provided and is used for billing purposes. Information for the federal reporting requirements is collected through a program census.

State Capsule:

# MISSOURI

**The State:**

Population: 5,117,073 (Rank: 15)

Size: 69,697 square miles (Rank: 19)

Number of counties: 114

**The Early Intervention System**

Program Name: First Steps

Lead Agency: Department of Elementary and Secondary Education

Number of infants and toddlers receiving early intervention on December 1, 1991: 1,323 (.58%)

The Department of Elementary and Secondary Education, the Department of Health, the Department of Mental Health, and the Department of Social Services are participating in the early intervention system. Services are obtained through either the Department of Mental Health which operates 11 Regional Centers for Mental Retardation and Developmental Disabilities or through the Department of Health's 10 Area Offices of the Bureau of Health Care Needs. Depending on the nature of the child and family's special needs, service coordination is provided through one of these two agencies. These agencies obtain early intervention services through a purchase of service contract with state-approved vendors in the area.

**The Data System**

Name: MoCARES (Missouri Care System)

The data system is run by the Bureau of Special Health Care Needs in the Department of Health. The system resides on the Department of Social Services' mainframe computer. Data for children with service coordinators from the Bureau of Health Care Needs are entered in the Regional Office computers which are connected to the state computer. Data for children with service coordinators from Mental Health are sent on paper to the state office and entered. Data in the system include family demographics and the IFSP. A variety of reports are generated by the system such as counts of children, population profiles, lists of children by diagnosis, case manager, and county. The early intervention data system is coordinated with services for children with Special Health Care Needs, Supplemental Food Program for Women, Infants, and Children, Childhood Immunizations, other Title V Block grant services and Medicaid. The coordinated system allows for restricted sharing of client information across agencies.

State Capsule:

# NORTH CAROLINA

**The State:**

Population: 6,628,637 (Rank: 10)

Size: 52,669 square miles (Rank: 28)

Number of counties: 100

**The Early Intervention System**

Lead Agency: Department of Human Resources (Division of Mental Health, Developmental Disabilities and Substance Abuse)

Number of infants and toddlers receiving early intervention on December 1, 1991: 8,853 (2.97%)

State agencies involved in the provision of early intervention services include the Department of Human Resources (Division of Mental Health, Developmental Disabilities and Substance Abuse, Division of Services for Deaf and Hard of Hearing, Division of Services for Blind, Division of Medical Assistance), Department of Environment, Health and Natural Resources (Division of Maternal and Child Health) and the Department of Public Instruction (Division of Exceptional Children's Services). Programs operated include a network of 18 Developmental Evaluation Centers which provide multidisciplinary evaluation, treatment and case managment services for children who have or are suspected of having developmental disablities; the Child Service Coordination Program which provides home visits, screening, family counseling, and developmental assessment for infants with risk indicators of developmental delay; and the Early Childhood Intervention Services which include home-based services, center-based services, and mainstreamed intervention programs.

**The Data System**

The state has been able to create a linked data set by combining separate data sets from the Department of Human Resources; the Department of the Environment, Health and Natural Resources; and the Department of Public Instruction. This linked data set is made possible because programs administered by these three departments all agreed to use a common unique identifier on their client records (first three digits of last name, first initial, date of birth). The common linked data set can provide an unduplicated count of children served and the services received from different agencies for each child. The agencies have also agreed to use a common set of data reporting forms to provide even more comparable data across agencies.

State Capsule: **OHIO**

**The State:**

Population: 10,847,115 (Rank: 7)

Size: 41,330 square miles (Rank: 35)

Number of counties: 88

**The Early Intervention System**

Lead Agency: Department of Health, Division of Maternal and Child Health, Bureau of Early Intervention

Number of infants and toddlers receiving early intervention on December 1, 1991: 12,711 (2.64%)

Four state-level agencies provide early intervention services: Health; Education; Mental Retardation and Developmental Disabilities; and Human Services. A myriad of private agencies also contribute to the early intervention service delivery system. Planning for expansion and improvement of community services takes place through 88 local collaborative early intervention groups (one in each county). The county interagency collaborative group provides the leadership in planning for a comprehensive system of early intervention services. Each county is developing a Child Find and Referral system with a single telephone number for primary referral sources. A single individual within the system single functions as a preliminary service coordinator until the IFSP is written.

**The Data System**

Name: Ohio Early Intervention Information Management System

The data system is a client-based management information system, and was developed in 1990 with a grant from the Office of Special Education Programs. It was implemented in four pilot sites in 1990-91 with full implementation across the state during 1991-92. The software is eitrac, a commercially available package for early intervention which runs on IBM-type microcomputers. Information entered into the system at the local level includes: client demographics; school district information; service information such as setting, IFSP dates, name of service coordinator, payment source and referral source; and referral information. The data entry process (i.e, the physical location of the computer, who enters the data) varies at the local level depending on the needs of the community. Data are transmitted from the local level to the state on floppy disks. Individual client-level data for a sub-set of the data elements are transmitted to the state. Children's names are included only if parent permission has been received.

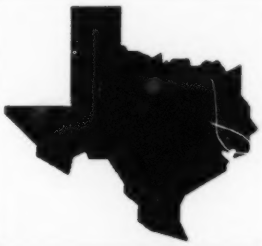
State Capsule: **TEXAS**

**The State:**

Population: 16,986,510 (Rank: 3)

Size: 266,807 square miles (Rank: 2)

Number of counties: 254



**The Early Intervention System**

Program Name: Texas Early Childhood Intervention Program

Lead Agency: Interagency Council

Number of infants and toddlers receiving early intervention on December 1, 1991: 7,429 (.83%)

The Departments of Health, Human Services, Mental Retardation, and the Texas Education Agency are participating in the early intervention system. An Interagency Council made up or representatives of each of these agencies and a public representative appointed by the Governor funds 77 local programs across the state. At the local level, agencies such as mental health/mental retardation, local school districts, state schools, educational services centers and private non-profit organizations operate early intervention programs. Funds are dispersed from the state to these program through a competitive bidding process. The state monitors service provision and provides training.

**The Data System**

The state collects several kinds of information from the local programs. Surveys conducted by the state include: the Quarterly Program Performance Reports (number of children referred, receiving services, etc. for program oversight and planning), the Once-A-Year-Survey (federal data reporting requirements), the Child and Family Questionnaire (goes to a 10% sample of families, examines demographic characteristics), the High Priority Infant Tracking System (information on the status of high risk infants), Personnel Surveys (submitted with the application for funds), and Monthly Services Report (professional and paraprofessional services and unit costs). Data from these surveys are automated for analysis at the state level. With the exception of the Child and Family Questionnaire, all data submitted to the state are program level data.

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